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Psychological Considerations and Interventions in Inflammatory Bowel Disease Patient Care

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Abstract

The presence of psychological comorbidities, specifically anxiety and depression, is well documented in IBD. The drivers of these conditions typically reflect four areas of concern: disease impact, treatment concerns, intimacy, and stigma. Various demographic and disease characteristics increase risk for psychological distress. However, the risk for anxiety and depression is consistent throughout IBD course and is independent of disease activity. Early intervention before psychological distress becomes uncontrolled is ideal, but mental health often left unaddressed during patient visits. Understanding available psychological treatments and establishing referral resources is an important part of the evolution of IBD patient care.

Keywords

Inflammatory Bowel Disease; psychology; mental health; psychotherapy; behavioral interventions

Introduction

Psychosocial challenges for inflammatory bowel disease (IBD) patients are critical considerations when managing care. These constructs have garnered much needed attention in recent years. However, psychological research only represents approximately 2% of all published IBD-related inquiry (74 of 4,470 articles indexed on PubMed in 2016) and translation of research findings to clinical practice is challenging. Considerable evidence shows IBD impacts health related quality of life¹, causes psychological distress², and psychological and behavioral interventions can mitigate some negative impacts to patient outcomes^{3,4}.

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Anxiety and depression are the most commonly researched psychological comorbidities in IBD. A 2016 systematic review reports the prevalence of clinical anxiety *disorders* is 21% in IBD patients while the prevalence of anxiety *symptoms* (e.g. sub-clinical scores on standardized anxiety measures) is 35%; rates of depression are somewhat lower, with 15% having a depressive disorder and 22% reporting depressive symptoms². Detailed reviews of anxiety and depression in IBD are conducted elsewhere. Rather, we aim to review potential psychosocial challenges for IBD patients within these two overarching, often-used terms and provide recommendations for appropriate interventions to mitigate negative impacts on patient care and outcomes.

Psychological Considerations in IBD

We know approximately one third of IBD patients experience anxiety and depression, but what is driving these symptoms? Drossman's 1991 study outlines four main areas of patient concerns: disease impact, treatment, intimacy, and stigma⁵. Subsequent research on IBD psychosocial issues generally tracks these domains, with additional nuance emerging as investigation in this area evolves⁶. Evidence based psychological treatments exist for most IBD mental health concerns. Of available psychotherapies, cognitive behavioral therapy (CBT), originally developed to treat depression⁷, shows consistent efficacy when applied to a wide range of psychiatric and medical conditions, including IBD, and may be effective in mitigating several of the psychological issues outlined in this review.

What is CBT?

In CBT, patients are taught to understand the relationship between situations, thoughts, behaviors, physical reactions, and emotions. Patients learn to change thoughts (through cognitive reframing), behaviors (through scheduled or prescribed changes in activity or responses), and levels of physiologic arousal (through relaxation exercises) in order to reduce emotional distress. In behavioral medicine settings, the CBT model is used to help patients cope with distress related specifically to a medical condition. In IBD, CBT has not been shown to consistently alter disease outcomes, but is effective in improving quality of life, coping skills, medical adherence, and underlying symptoms of anxiety or depression⁸. As such, as we outline psychological distress in IBD patients, potential CBT-based interventions are proposed in Figure 1.

IBD Impact

Disordered Eating

Food is a fundamentally important aspect of life that can pose particular challenges for IBD patients. A majority of patients hold strong beliefs about how food impacts their illness, but many do not receive adequate help^{9, 10}. Many IBD patients determine what foods are "safe" versus "unsafe" based on subjective experience^{11, 12}. Some turn to one of many popular exclusion diets. Following long-term dietary regimens can produce maladaptive attitudes, including anxiety, toward food¹³. While clinical eating disorder pathology (i.e., anorexia nervosa) is possible, the more common risk in IBD is development of *disordered eating (DE)*, or dysfunctional eating behaviors such as skipping meals, binge eating, restricting, and

fasting¹⁴. We recommend The Food Related Quality of Life Questionnaire to assess IBD patient eating concerns.

People with GI illness, including IBD, are at higher risk for developing DE which associated with increased psychological distress and symptom severity¹⁵, and is independent of remission status¹⁶. Patients may limit social interactions to mitigate food anxiety, which in turn increases psychological distress, creating a vicious cycle^{16,17}. Depending on how restrictive the diet is, nutritional deficiencies may develop from DE, further complicating treatment. Over-nutrition is also a growing problem in IBD with rates of overweight and obesity similar to the general population^{18, 19}, especially in patients with mild disease or in remission. IBD patients are susceptible to DE habits which may increase caloric intake including binges or emotional eating associated with anxiety or depression.

Insomnia and Fatigue

Sleep is important in IBD management as insomnia is known to impact both physical and psychological well-being. A large body of research demonstrates sleep problems are associated with poorer outcomes in anxiety and depression²⁰ and insomnia predicts future mental health problems in individuals without current psychological distress²¹. Fatigue is one of the most burdensome IBD symptoms²² and is highly prevalent, with 44–86% of patients with active disease and 22–41% with inactive disease reporting clinically significant levels of fatigue^{22–24}. Being female, psychological distress, disease-related worry, low quality of life, disability, and poor sleep quality are all associated with greater fatigue. Two measures of IBD fatigue include the Inflammatory Bowel Disease Fatigue Scale and the Multidimensional Fatigue Inventory.

Post-Traumatic Stress Disorder

To date, no study evaluates post-traumatic stress disorder (PTSD) in IBD. However, based on the nature of IBD it is plausible PTSD may be present in a subset of patients. PTSD symptoms may increase over time or be intermittent throughout the course of illness and include intrusive thoughts, nightmares, or flashbacks²⁵ avoidance of thoughts or feelings related to the trauma, social withdrawal, and emotional numbing²⁵. There are multiple risk factors for PTSD including heightened psychological distress following diagnosis, female sex²⁶, lower socioeconomic status²⁷, more severe disease²⁸, uncontrolled pain, younger age at diagnosis^{28, 29}, type of surgery, subjective intensity of symptoms³⁰, and at least one disease recurrence.

Compared to trauma associated with combat or natural disasters, the PTSD-stressor in IBD comes from an internal event (i.e. the disease), as such the IBD patient cannot flee the actual threat. Avoidance behaviors may manifest in treatment non-adherence^{31–33} or missed follow-up care³⁴ as these may be triggers of intrusive symptoms. Conversely, PTSD may drive health-related anxiety resulting in excessive healthcare utilization and costs³⁵ due to somatic symptoms or pain perception³⁶ not associated with IBD disease activity. PTSD is also associated with enhanced cellular immune response³⁷ and alterations to the hypothalamic-pituitary-adrenal (HPA) axis³⁸, thereby complicating its relationship with IBD

disease course. Rapid assessment tools exist to screen IBD patients for PTSD, including the Primary Care PTSD Screen and PTSD Checklist – Civilian Version.

IBD Treatment Concerns

A recent paradigm shift in IBD treatment outlines top-down (i.e. biologic medication first) versus traditional bottom-up approaches³⁹; 24% of IBD patients were current or past users of biologic medications in 2014⁴⁰ with increasing trends of use⁴¹. Starting a biologic medication may cause distress in some patients. Escalation in therapy may serve as a sign of worsening disease⁴². Some patients may be afraid of potential side effects of biologic therapies while others may be more tolerable of risk than their physician⁴³. Injection anxiety is an underdeveloped area of research in IBD but is associated with lower medication adherence in other illness groups^{44, 45}. If anxiety poses a barrier to initiating or adhering to a biologic, or other IBD medications, traditional CBT or behavioral self-management (outlined below) are effective treatments.

Intimacy Concerns

Body image

Up to two thirds of patients with IBD report some body image dissatisfaction^{46, 47}, with higher rates in women (75% versus 50% of men). Dissatisfaction is related to weight loss, hair loss, weight gain from corticosteroids, extra-intestinal dermatologic manifestations, increased disease activity, high symptom burden, longer duration of steroid use, other extra-intestinal symptoms including fistulas, and surgical history^{47, 48}. Negative body image is logically associated with decreased quality of life and increased psychological distress^{46, 49}, however it is infrequently discussed during routine medical visits. The 9-item Body Image Scale is recommended for assessment.

Sexuality

Up to 31% of men and 80% of women with IBD report low or no interest in sex^{50, 51}. Depressed mood is the strongest predictor of sexual dysfunction across genders. Patients with prior surgical resection report lower libido and less frequent sexual activity compared to non-operated patients⁵². Permanent ostomy also impairs sexual functioning in both men and women, with an increased rate of anorgasmia in female ostomy patients. Longer disease duration is associated with fewer sexual problems, possibly due to increased coping skills over time⁵⁰. Twenty-five percent of females report pain during intercourse, which is not associated with disease type or activity, use of steroids, or presence of perianal disease and may be related to pelvic floor dysfunction. Unfortunately, many providers do not inquire about sexual functioning during regular visits⁵³. In a survey of 64 women with IBD, only 12 (18.8%) had discussed sexuality/sexual functioning with their gastroenterologist, and of those who did, 100% were patient-generated conversations. Several validated assessment tools exist including the Sexual Functions Questionnaire, International Index of Erectile Function, and Female Sexual Function Index.

Childbearing Concerns

Many women with IBD report a higher rate of voluntary childlessness^{54, 55}: 18% in CD and 14% in UC compared to 6.2% in the general population. Primary motivators include worry about IBD heritability, risk of congenital abnormalities, and medication teratogenicity. Common pregnancy concerns, which are associated with poor understanding of actual risks of pregnancy with IBD⁵⁶, include infertility, effects of medications on the fetus, vaginal delivery versus cesarean section, and breastfeeding⁵⁷. However, only 28% of women with IBD demonstrate “good” to “very good” knowledge in these areas⁵⁸.

Stigma

While stigmatization is widely studied in HIV/AIDS and mental illness, research into IBD-related stigma is relatively new. A 2016 comprehensive review of IBD stigma finds IBD patients perceive that others hold stigmatizing views toward them and the disease, some patients internalize these negative beliefs while others resist them, and stigmatizing attitudes and behaviors exist among those without IBD^{59, 60}. Like stigma toward other diseases, IBD stigma is associated with poorer outcomes⁶¹ and may cause or exacerbate feelings of depression or anxiety. Clinicians should be mindful of potential stigma being experienced by their patients and inquire about its impacts on social experiences and interpersonal relationships.

Integrating Mental Health into IBD Patient Care

This review, as several others, demonstrates IBD patients have mental health needs that, if unchecked, can have direct and indirect impacts on patient outcomes. Yet, integration of behavioral medicine services into gastroenterology practice is limited, mostly to tertiary, university-based centers in major metropolitan areas. How, then, can the vast majority of gastroenterologists ensure effective management of the mental health issues of their patients?

Psychological distress over the disease course of IBD is consistent and can be independent from disease activity⁶², so merely treating IBD symptoms is insufficient in its alleviation. Newly diagnosed patients have the greatest need for psychotherapy⁶³ and early intervention, before the patient is significantly distressed, leads to better outcomes⁶⁴. Unfortunately, several barriers exist including social stigma, financial burdens, and a lack of mental health professionals trained in working with IBD patients⁶⁵, preventing timely referral to a mental health specialist; only 15% of IBD patients report referral for mental health treatment while half would desire such referral⁶⁵.

Two 2017 studies find most patients and providers do not discuss how IBD may affect quality of life, emotional functioning, and overall mental health during routine visits⁶⁵, both in the U.S. and Europe⁴²; seventy-five percent of patients would like their providers to address these impacts. Gastroenterologists may feel compelled to try to treat mental health themselves, feel unsure of how to broach the topic of mental health, not detect psychological distress⁶⁶, or prioritize other disease management issues due to appointment time constraints⁶⁷.

In the era of the rapid medical encounter, it is vital for the practicing gastroenterologist to efficiently recognize potential psychosocial issues that may impact patient outcomes and establish a referral process for reliable and reputable mental health treatments. Figure 2 provides recommendations for streamlining referrals to mental health services. In addition to CBT approaches previously described, additional psychological interventions are available and may be efficacious for some IBD patients.

Behavioral Self-Management

For patients who do not exhibit psychological distress and/or who are not interested in traditional psychotherapy, Behavioral or Self-Management Therapy may be effective^{68, 69}. In this treatment, the goal is to target negative health behaviors (e.g. poor medication compliance, dietary non-adherence) to improve overall physical health. This therapy is informed by the CBT model but does not incorporate the cognitive component of traditional CBT, which evaluates negative or distressing thought patterns.

Medical Hypnotherapy

Medical hypnotherapy is an effective intervention for many diseases and disorders. Gut-directed hypnotherapy is a variation of medical hypnotherapy that focuses hypnotic suggestions on the health of the gastrointestinal tract^{4, 70, 71}. This treatment typically involves 7–12 weekly sessions where patients learn to achieve a deep hypnotic state and are then led through a series of scripted, gut-focused imageries with suggestions. Patients practice these exercises at home using audio recordings. Recent pediatric research suggests self-directed hypnotherapy is as effective in treating functional abdominal pain and irritable bowel syndrome as treatment with a clinician⁷², which would make this treatment more accessible.

In IBD, a handful of studies (limited by small sample sizes) evaluate the efficacy of gut-directed hypnotherapy. Findings show reduced rectal mucosal inflammatory responses (IL-6, IL-13, TNF- α , substance P, histamine) in patients after one session⁷³, prolonged clinical remission by approximately 2.5 months in patients with quiescent UC compared to controls after 7 sessions of hypnotherapy⁷⁴, and maintained remission in one quarter of patients with active IBD at 5 year follow up after 12 sessions⁷⁵.

Telemental Health

Telemental health interventions are a promising alternative for IBD patients needing behavioral intervention. Four studies on web-based interventions exist for IBD⁷⁶. The existing literature is promising, suggesting improved outcomes in IBD with use of these interventions^{77, 78}. Web-based psychological interventions are effective in treating depression and anxiety^{79–81}, insomnia⁸², and irritable bowel syndrome^{83, 84}. These strategies may bridge the treatment gap that currently exists for integrated behavioral medicine practice in gastroenterology.

Conclusions

Psychological considerations are vital for proper IBD management as IBD patients experience a complex interplay between their physical and emotional health. While there is a dearth of GI psychologists at present, identifying mental health clinicians with chronic illness experience trained in evidenced-based interventions such as CBT should be a priority. Patients express desires for, at a minimum, conversations about IBD's impact on quality of life and emotional well-being yet these needs remain unmet in most. While these topics may be difficult or potentially time consuming, left unchecked psychological distress can hamper disease and symptom management. As IBD treatment continues to evolve, giving appropriate credence to the psychology of the IBD patient will lead to improved patient satisfaction and care.

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Key Points

- Psychological health is an important yet neglected aspect of IBD patient care, with challenges in identifying proper treatments and mental health resources.
- Psychological distress typically occurs due to disease impact, treatment concerns, intimacy concerns, and stigma. Left untreated, psychological distress has direct negative impacts on patient outcomes.
- Several evidence-based treatments are available for most causes of psychological distress in IBD patients, the most widely accepted being rooted in cognitive behavioral theory.
- Patients want their gastroenterologist to discuss psychological issues during routine visits, and many are open to or desire referral to qualified mental health providers for concurrent treatment.

<p>Disordered Eating</p> <ul style="list-style-type: none"> • Traditional CBT for DE • Enhanced CBT (CBT-E) if clinical eating disorder present • Intensive outpatient or inpatient eating disorder center
<p>Insomnia</p> <ul style="list-style-type: none"> • CBT for Insomnia (CBT-I) • Medical Hypnotherapy • Sleep Healthy Using the Internet (SHUTi) http://www.myshuti.com
<p>Fatigue</p> <ul style="list-style-type: none"> • Traditional CBT • Behavioral self-management
<p>PTSD</p> <ul style="list-style-type: none"> • Cognitive Processing Therapy • Prolonged Exposure Therapy • Select psychotropic medications • http://www.ptsd.va.gov/professional/treatment/overview/
<p>Treatment Concerns</p> <ul style="list-style-type: none"> • Traditional CBT • Behavioral self-management
<p>Intimacy Concerns</p> <ul style="list-style-type: none"> • CBT for sexual dysfunction • Medical hypnotherapy • Pelvic floor physical therapy • Education about IBD and pregnancy
<p>Stigma</p> <ul style="list-style-type: none"> • Individual or group CBT • Educational programs for family, friends, significant others

Figure 1.
Evidence Based Behavioral Interventions for IBD Mental Health Concerns

Know Your Resources

- Generate a referral list of qualified mental health professionals in your area that are easily accessible in clinic. See the Resources section for directory recommendations.
- Seek clinicians with specialization in clinical health psychology or behavioral medicine and who primarily utilize a CBT treatment approach.

Therapist Directories

- Psychology today therapist finder: <https://therapists.psychologytoday.com>
- Directory of Cognitive Behavioral Therapists: <http://www.abct.org>
- Society of Behavioral Medicine: www.sbm.org
- Gut-Directed Hypnotherapy Providers: <http://www.ibshypnosis.com>

Have the Discussion

- Establish a solid therapeutic alliance with open communication with each patient.
- Discuss social & emotional aspects of IBD early, even in the absence of overt distress.
- Ask patients about stress, mood, anxiety, and intimacy regularly to ensure early intervention.

Integration of Care

- Communicate with mental health providers working with your IBD patients to ensure continuity of care.
- Ask patients about their experience with mental health treatment once referred.

Figure 2.
Integrating Mental Health Services into IBD Patient Care